# Community Research: Partnership in Black Communities

John Hatch, MSW, DrPh
Nancy Moss, PhD
Ama Saran, MSW, MPH

Letitia Presley-Cantrell, MEd
Carol Mallory, BEd

Finding common ground for forming relationships between researchers and a particular community can increase the relevance of research as a resource for setting priorities and developing strategies for change tailored to the interests and needs of the community. In the 1990s, research is expected to increase in U.S. populations that experience a disproportionate burden of disease, disability, and premature death. James Mason, former assistant secretary for health, has argued that redoubling research efforts in minority communities is essential for achieving the Year 2000 Health Objectives.[1] The potential benefit is also greatest in higher-risk populations. Since large proportions of preventable diseases and deaths are caused by factors that can be changed by motivated individuals supported by friends, family, and community, progress toward reaching the Year 2000 Objectives will require greater insight by researchers into the behavior, motivation, and relationships of people at the grassroots level.

Collaboration is especially important when each party has a stake in the design of studies and the orientation and interpretation of research findings—for example, research on the academic achievements of black youth, investigation into drug abuse among black women, and studies on the causes of poverty. The importance of this collaboration also arises from the fact that if those who form hypotheses are from different cultures from those being studied, ambiguity resulting from a limited understanding of local culture can cause a biased interpretation of observed behavior. For example, a study on health care systems in rural Georgia found that the perceptions of the numerically small but powerful upper middle class defined the health problem and thus directed the selection of

the intervention.[2] Further, observation of religious worship services, parenting, courtship, youth gang rituals, and other social behavior in ethnic and minority subcultures has resulted in biased interpretations of the meaning of these activities in the lives of those being observed.[3,4] Bias has important implications concerning how well a program will be accepted in a community.

Community insiders are certainly experts in the social meaning of disease and can help researchers identify relevant issues, causal mechanisms, and implementation of acceptable interventions.[3,5,6] Behaviors that appear chaotic and irrational to outsiders may seem rational and normal to the insider.[4] Because the social meaning of events can often be understood best within the context of the history of a community,[7] members of the community are best capable of evaluating and communicating that meaning.

This article explores four potential models for collaborative research in black communities in the United States and their attendant challenges to the community and to the scientific approach. We present the perspective of health educators, research scientists, and community activists who have an interest in community-based research.

## Models of Community Research

Throughout this discussion it is important to keep in mind what we mean by "community," in particular the black community. The "black community" as a unit of identity for black Americans is *not* the same as geographic/demographic clusters in which the majority of the people are black. Places demarcated by natural or psychological boundaries serve as a common core of commercial and human service organizations, churches, and schools, and, where the population is all black or predominantly black, are called black communities. However, community can be defined also by shared interests, common fate, social and political history, and cultural affinity. Blacks share a bond to the history, ethos, and institutions that form the heart and soul of the identity known as the black community. Even though black communities are by no means homogeneous geographically, the experience of being black in America has produced sentiments and experiences that have molded a sense of "peoplehood." A sense of peoplehood, formal or infor-

mal ties to religious and social organizations, and family conceptually define the black community for the majority of African Americans. Researchers seeking community models must consider both the geographic boundaries of the black community and the sense of cultural identity that also unites it.

These black communities may be poor, working class, middle class, upper class, or of mixed socioeconomic status. Their social organization ranges from organized and stable to disorganized and transient. Styles of leadership, patterns of social organization, and internal coherence will vary in accordance with past and present events and traditions within the community and in the broader society.

The challenge for researchers is to design models for collaboration that maximize the potential for community participation. In the first model, the persons the researchers consult for advice and consent are at the periphery of community cultural systems; often they work for human service organizations and usually live outside the community. In such instances, the research is community based but fails to achieve optimal involvement because the people of the community remain unaware of the purpose of the research and have no influence on research design.

In the second research model, researchers identify influential people within community cultural systems (e.g., churches, clubs, fraternal orders, and civic associations) to whom they explain the research design and from whom they request endorsement and cooperation. The researcher retains total control of the project. This model is community based, but the community role is essentially passive.

In the third model, researchers contact influential community leaders to explain the research and to ask for support, advice, and guidance in hiring community people as interviewers, outreach workers, and screeners. These influential people may be invited to serve on an advisory board. This model is community based but not community involved, since community members do not contribute to the design of the research nor do they have a significant role in interpreting findings. This model achieves greater community involvement, but its potential for manipulating communities is greater, as well, because those selected for employment with the project are often trusted and influential members of the local cultural systems.

An example of this third model is a community-based program designed and conducted in 1985 in East Baltimore by the Johns Hopkins medical institution and community leaders. This program was designed to control hypertension and related cardiovascular risk factors in a predominantly black inner-city population. A task force that included representatives from city hall, churches, schools, the city health department, and Johns Hopkins Medical School provided oversight. During the time period of the program, hospitalization for hypertension declined by 30%. Much of the success of the model was attributed to the recruitment and training of community residents as certified health workers skilled in community outreach, counseling, and monitoring blood pressure.[8]

Another example of the third model is a study begun in 1978 by health educators at the University of North Carolina. The goal of this community education project was to increase use of health care resources for control of hypertension and diabetes. The intervention called for training community-selected volunteers as health advocates who would share information with others in their social networks and play a facilitating role in

linking individuals with resources. Project staff asked for community input, especially from those in leadership positions in black churches, to help define project objectives. These discussions resulted in expanding the intervention to include rodent control in one neighborhood; in another community, people insisted on changing traffic flow at a dangerous railroad crossing. Two years after beginning the project, an evaluation indicated higher levels of knowledge about the cause and prevention of the targeted diseases. Competency in reaching out to health professionals and others able to help in solving local problems increased. Before the health project, the vast majority of community members had never made demands to local governments or service agencies. The project directors believe that acquisition of skill in self-advocacy will eventually have a greater impact on the overall quality of community life than on the disease-specific conditions that stimulated the intervention.[9–11]

Two potential pitfalls beset this third model. One is the process by which community advisers or partners are selected. They may not represent the community as a whole but only special interests. The second pitfall involves the manipulation of community members who could sanction unethical or unscientific projects, unknowingly. These projects could then escape critical scrutiny and perhaps receive endorsement from local and broader-based black-interest advocacy groups. Poor communities might perceive employment of a few people as justification for research, without assessing the research program's possible benefits and liabilities to the community as a whole.

The fourth model is best suited for research in black communities because it both involves and enables the community. In this model, the researcher seeks community assistance in setting the direction and focus of the research. The problem to be studied is defined and the research design is constructed after the community to be studied is consulted for its definition of the problem, its analysis of contributory factors, and its potential solutions. The research design enfolds the experiences and knowledge of the people who will be studied rather than bypassing them in favor of a research agenda defined solely in relation to scientific protocol. The community thus becomes a collaborator in the research. The community also negotiates, as a collaborator, the goals of the study, the conduct of the study, and the analysis and use of study findings. Community members know beforehand what to expect from their research efforts as collaborators. Therefore, this model becomes not just community based but community involved, as well.

An example of a community-university project exhibiting these characteristics was carried out by Hatch et al. at the University of North Carolina School of Public Health in the early 1980s. The project was funded by the American Heart Association (AHA) to test the benefit of aerobic exercise on cardiovascular fitness in a population of black women. The researchers' primary goal was to understand how to gain sustainable community participation in cardiovascular fitness activities; the participants' primary goals were to feel better and look better. These multiple aims did not conflict, but the dual agenda required more time to conduct the research than research focused solely on the researchers' objective of cardiovascular fitness. The AHA's evaluation followed a biomedical protocol. The researchers were interested in the psychosocial dynamics of gaining participation and sustaining involvement. The measure of success for the participants was their ability to

achieve a reduction in waist size. The participants organized a fashion show at local churches to show off their achievements. The three-year funding ended in 1988, but services initiated through the project have continued through volunteer fitness leaders and an advisory board of community members and health professionals.[12]

## Challenges to the Black Community When Forming a Research Partnership

The community must act to protect its own needs and interests in any research collaboration, including selecting a research problem that has social significance for the community, assuring the physical safety of community participants, preventing socially damaging uses of scientific data, and assuring long-term social benefit to the community by establishing a community-based infrastructure to continue interventions.

To implement community-research partnerships, we need strategies for understanding the internal functioning of the microcommunity (local) in the context of its relationship to the broader, macrocommunity (macro) of black people. Identifying uniqueness at the micro level requires insights best acquired when local people are involved in setting the research agenda.

Interests of the researcher and the community are likely to differ. The community is most likely to be attracted to the potential of using research to solve immediate social problems, whereas the researcher and the funding agency seek information for scientific or policy purposes. Investigators who can include community issues in their research agenda will be more likely to find support in the community. In those black neighborhoods that have been of particular interest to public health researchers, most residents are aware of the need to improve their quality of life and of the helping role science can play. However, the community should reject research narrowly focused on scientific issues peripheral to the concerns of the people because scarce resources and the finite energy of leaders should not be used for pursuits that do not directly benefit the community. Ignoring local community concerns is likely to compound the sense of frustration that is all too often the by-product of unrewarded collaboration. A related problem, which both scientists and the local community need to address, is the tendency to design research that fails to look beyond the individual and the local community to the broader issues of social policy, values, and the equitable distribution of public goods and services, such as education, health care, law enforcement, and recreation.

The challenge of protecting study populations has been fairly effectively dealt with by organized science, as represented by the National Institutes of Health, the Centers for Disease Control and Prevention, universities and medical schools, and similar organizations such as hospitals and research institutes. Institutional review boards, human subjects committees, and explicit policies on the part of funding organizations help reduce the potential harmful effects of research, encourage informed consent, recognize confidentiality, and, most recently, require samples that represent the population's characteristics (gender, race, and ethnic origin).

Many members of the black community, however, still distrust scientific research directed at black people. The Tuskegee study is often cited by those who warn against cooperation with researchers. That study of untreated syphilis in black men is the longest nontherapeutic experiment in American medi-

cine.[13] Study participants were intentionally harmed because they were told that they were receiving treatment for "bad blood" but actually were only undergoing diagnostic tests to determine the effects of syphilis.[14] Even now, in some black communities, one third of the population may believe that acquired immunodeficiency syndrome (AIDS) is a form of genocide.[13] In a social context of inequality and neglect, human immunodeficiency virus as a weapon of racial warfare is believable to some people.

Data interpretation is a major source of concern for the black community. Biomedical, social, and behavioral sciences research has been used to support negative stereotypes of racial inferiority and to justify racial separation and social neglect. Examples are Jensen's research on black children,[15] Shockley's work on intelligence,[16] and the Moynihan report on black families.[17] These studies were variously driven by the beliefs that group capacities to learn are predetermined by race, biological endowment is racially determined, failure to thrive is grounded in group pathology, and environmental influences explain few differences between blacks and whites in educational achievement, health status, and income.

Research projects that leave no organizational structure capable of continuing beneficial activities in the community contribute to the community's distrust of the research establishment. For example, when the funding for the Johns Hopkins/East Baltimore program ended, the research staff abruptly withdrew. A year later, the advisory board stopped meeting, and the overall activity declined. There was no community-based organizational structure capable of independently continuing the program after the researchers withdrew. After more years of work to refine the project model with community input, a relationship based on trust between the community and the university is now developing.

In 1986, a potentially effective approach for developing long-term community capacity began when the Henry J. Kaiser Family Foundation encouraged communities across the nation to pursue risk reduction/health promotion projects suited to their interests and special needs.[18,19] Announcements about the program were broadly distributed, resulting in hundreds of requests for support. Planning began on the initiative of microbased or macrobased organizations. However, the foundation required organizations to seek cooperation and participation from other organizations with an identified or potential interest. Kaiser apparently wished to assess the efficacy of community-initiated and community-sponsored health promotion as a means to change national health care priorities. The foundation committed $15 million to the project and invited other foundations to join in supporting the effort. Evaluation of this major effort is still in progress; publication of findings is expected within the next year.

During the start-up phase of these projects, the Kaiser Foundation provided technical assistance to communities in planning and evaluation through regional conferences for potential grantees. Those requiring more sustained input were assisted by community health promoters associated with resource universities located in several regions of the nation.

A current project based on a three-way model of interaction among the funder, the researcher, and the community is testing the theory that misunderstandings among participants about motivations and the expected outcome of a project cause conflict. This model promotes open negotiation among those who hold a stake in the expected outcome as well as joint participa-

tion in design and evaluation (Tony Whitehead, The Cultural Systems Analysis Group of the Department of Anthropology, University of Maryland, College Park, personal communication, 1991).

Thus, collaborative research is empowering and enabling—not simply advisory in nature. In many communities, it will take time to establish trust and build the knowledge base needed for substantive contributions to the scientific design, implementation, and critical interpretation of collaborative research. Fortunately, today a cadre of minority professionals in the social, behavioral, and biomedical sciences expressly monitor and advocate actions in their respective disciplines that affect minority populations. Community attitudes may still be cautious, even toward minority researchers. However, black researchers' links with organizations of the broader black community may help overcome this obstacle.

## Challenges to the Scientific Community When Forming a Research Partnership

What challenges to scientific values and methods does community collaboration in research present? One challenge is to determine to what extent the rigor of science must be protected. For example, must science always use an experimental or quasi-experimental design on random samples of populations? How will populations be defined? Are there circumstances when storytelling, ethnography, and qualitative methods enhance science? What are those circumstances and what guidelines can direct their adoption and use?

Scientists generally have perceived the positivist scientific tradition as "value-free"—that is, with sufficient application of scientific rigor (as defined by the scientific elite), neutral knowledge will result (many philosophers of science and sociologists have not shared this perception). Community involvement in, if not control over, the research process could be viewed by scientists as potentially threatening to the neutrality of science. During the 1960s and 1970s, there were a number of philosophical challenges to this value-free approach, particularly in the social sciences,[20] but it has continued to dominate the ideology, if not the practice, of scientific research.

However, by including the community as a coparticipant in the definition of the problem and in the formulation of hypotheses, the researcher can meet the real world, perhaps to the enrichment of science. Conversely, community members' own concerns can best be served by logical hypotheses and "clean" methodology. For example, during the late 1980s, a cluster of childhood cancer cases occurred in a relatively middle-class area of San Francisco. Concerned residents held meetings, inviting scientists, the media, and the public to attend. As a result, community members asked epidemiologists to investigate the cancer cluster. In the process, community residents learned how to measure environmental and social links to childhood cancer. In turn, the epidemiologists could pursue their research.[21] Community instigation of epidemiologic investigations like this one have led to major advances in public health and scientific knowledge.

Adequate protection of the rigor of scientific process may be the heart of the challenge that active community involvement in research poses for scientists. Fundamental characteristics of good science include precisely stated research questions; a clearly identified population and sample within the population; replicable methods, including sampling, measures, and data

analysis; and results interpretable within the frame of the existing scientific literature. A community or target population may not always understand or sympathize with scientific aims and methods. For this reason, scientists should explain to the community the rationale for using them through communication within a partnership rather than through cooptation, and, in return, the community must educate the scientist about its concerns.

An unavoidable risk of good science (that is, science in which research questions, data, and methods are not manipulated to produce certain answers) is that the data may be open to a number of interpretations. Communities may have less involvement in and control over the data their involvement has generated than they desire. In some cases, the findings may not be what the community wants to hear. Many highly volatile research questions concern the relationship between race/ethnicity and health outcomes. Some community-instigated epidemiologic investigations did not discover the relationship community members expected to find between an environmental hazard and an outcome.[21] In such cases, the community may be concerned that "no results" could open the door to further contamination. Another problematic situation occurs when the evaluation of a popular intervention shows weak or no results, which could lead to termination of a program or to policies unpopular with the community. Scientists should thus explain clearly the value of negative as well as positive results to the development of general knowledge. Scientists thereby preserve the specific contribution that the scientific method can make to understanding while clearly distinguishing it from the contributions of other disciplines, including health and social policy.

## Research and Potential Partnerships in the Community of African-American Women

The fundamental issues that should guide public health research on the lives of contemporary African-American women are the same ones that guide any gender-sensitive, responsive research agenda. African-American women should be characterized by the social and cultural conditions that differentiate their lives: infrastructure inequities, primarily economic and political; the consummate effects of sustained cultural erosion; and relationships of resistance and power, powerlessness, and privilege. These "differentials" form a core of common experience of African-American women in this country. In addition, the shared experience of gender difference as well as racial and cultural difference are present in all aspects of life for African-American women. These differences should be taken into account in public health research.

Much of the shared positive experience of African-American women should be captured in community-involved research. In the traditional black community, women transmit attitudes toward maintaining good health through the telling of the story of their lives and the lives of their ancestors. The cultural meaning of health within the context of the ways African-American women lead their lives, as described by the women themselves, should inform research activity designed to develop appropriate health intervention strategies.

Public health research should move away from the reductionist approach frequently used in social science research to explain the life circumstances of African-American women. This approach often presents a deficit model that emphasizes negative outcomes and adverse risk factors, with no inclusion of

protective factors and no understanding of the meaningful, important factors in African-American culture that contribute to positive health outcomes for many African-American women. African-American women should tell their own stories, sort out their own explanations of what contributed to their adverse health outcomes in collaboration with the scientific community. Discussion should present the problems of women as they perceive them and explore black women's responses and solutions.[22]

Community-involved research is necessary for developing appropriate intervention strategies that include African-American women's holistic approach to the definition of health. This research will provide the information needed to craft and implement socially sensitive, politically powerful, and culturally accountable plans, policies, and programs that ensure the inclusion of African-American women's vision.

Research partnerships in the community should sponsor more female leadership and provide critical mentoring and professional development to support and sustain that leadership. Thus, research can become an effective and innovative way to garner moral, political, and material support for social change.

## CONCLUSIONS

Community collaboration with the scientific community provides the opportunity for creative problem-solving. Science as a discipline is currently undergoing dynamic change as diseases such as AIDS set in motion new client-professional relationships.

In this new social and political context, the scientific community stands to gain enhanced access to communities of concern—those most vulnerable to poverty and disease. The opportunity arises for communities and science to work in tandem to ensure a more balanced set of political, social, economic, and cultural priorities, which satisfy the demands of both scientific research and communities at higher risk.

Questions involving science and the community are not mere sources of traditional academic debate. What each does affects human lives with critical consequences for all. The community's greatest impact on science will be to make it more difficult to assume the objectivity of the scientific process. We can now begin a social process wherein a search for scientific answers does not become a justification for exclusion and elitism. The community's role in this process will force us to examine the social and political contexts crucial to formulating whole problems and deriving effective answers.

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